

Cancer Registries:

The Foundation for Cancer Prevention and Control



"Having complete, timely, high-quality cancer data from throughout the United States is essential to identifying, understanding, and controlling our nation's cancer burden."

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Chronic Disease Prevention
and Health Promotion

The Nation's Cancer Burden

According to the American Cancer Society (ACS), more than a half million Americans will die of cancer in 2003—that is more than 1,500 people a day. One of every four deaths in America is from cancer. About 1.3 million new cases of cancer will be diagnosed in 2003. This estimate does not include diagnoses of in situ (preinvasive) cancer or the approximately 1 million cases of nonmelanoma skin cancer that will be diagnosed this year.

The National Cancer Institute (NCI) estimates that about 8.9 million Americans with a history of cancer were alive in January 1999. Although some of these individuals were

considered cured or cancer free, others continued to live with the disease and may have been receiving treatment.

Effective strategies exist for reducing new cases of cancer and deaths caused by cancer. These include decreasing the prevalence of behavioral and environmental factors that increase people's cancer risk, and ensuring that evidence-based screening tests and treatment services are available and accessible. Resources that can be devoted to such strategies are limited, however, and must be allocated wisely. Wise resource allocation, in turn, depends partly on the availability of complete, timely, and high-quality cancer data.

Cancer Registries: Essential to Reducing the Burden

Cancer registries collect information about the occurrence (incidence) of cancer, the types of cancers that occur and their locations within the body, the extent of cancer at the time of diagnosis (disease stage), and the kinds of treatment that patients receive. These data are reported to a central statewide registry from various medical facilities, including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories.

Data collected by state cancer registries enable public health professionals to better understand and address the cancer burden. Registry data are critical for targeting programs focused on risk-related behaviors (e.g., tobacco use and exposure to the sun) or on environmental risk factors (e.g., radiation and chemical exposures). Such information is also essential for identifying when and where cancer screening efforts should be enhanced and for monitoring

the treatment provided to cancer patients. In addition, reliable registry data are fundamental to a variety of research efforts, including those aimed at evaluating the effectiveness of cancer prevention, control, or treatment programs.

State cancer registries are designed to

- Monitor cancer trends over time.
- Determine cancer patterns in various populations.
- Guide planning and evaluation of cancer control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference).
- Help set priorities for allocating health resources.
- Advance clinical, epidemiologic, and health services research.
- Provide information for a national database of cancer incidence.



DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention

CDC's National Program of Cancer Registries

Providing National Leadership

The Centers for Disease Control and Prevention (CDC) has administered the National Program of Cancer Registries (NPCR) since 1994. This program is currently helping states and U.S. territories to

- Improve their cancer registries.
- Meet standards for data completeness, timeliness, and quality.
- Use cancer data to support cancer prevention and control programs.
- Train registry personnel.
- Establish computerized reporting and data-processing systems.
- Develop laws and regulations that strengthen registry operations.

Before NPCR was established, 10 states had no registry and most states with registries lacked the resources and legislative support needed to gather complete data. With

fiscal year 2002 funding of approximately \$40 million, CDC's NPCR supported central registries and promoted the use of registry data in 45 states, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands. CDC also developed special research projects such as studies to examine patterns of cancer care in specific populations. CDC's goal is for all states to maintain registries that provide high-quality data on cancer and cancer care.

NPCR complements NCI's Surveillance, Epidemiology, and End Results (SEER) registry program. Together, NPCR and the SEER program collect cancer data for the entire U.S. population. The SEER program gathers in-depth data on cancer cases diagnosed in Connecticut, Hawaii, Iowa, New Mexico, and Utah, as well as in six metropolitan areas and several rural/special population areas. The six metropolitan SEER registries and some of the rural/special population registries submit data to NPCR's state registries. In 2001, SEER began providing additional support to four NPCR-supported state registries (California, Kentucky, Louisiana, and New Jersey).

Expanding Efforts to Improve and Use Cancer Data

Assisting States

CDC provides leadership and support to improve the quality of cancer registry data and to use these data for cancer control planning. The agency does this by

- Providing technical assistance to registries to help ensure data completeness, timeliness, and quality. (For example, CDC has developed software to facilitate data transmissions and improve the quality of data that hospitals transmit electronically to cancer registries.)
- Coordinating and convening meetings of registry personnel for information sharing, problem solving, and training.
- Helping states and national organizations use cancer data to describe state and national disease burdens, evaluate cancer control activities, and identify populations at risk for certain cancers.
- Collaborating with federal, state, and private organizations to design and conduct research using data collected through state registries.

Ensuring the Quality of Registry Data: CDC Standards and NAACCR Certification

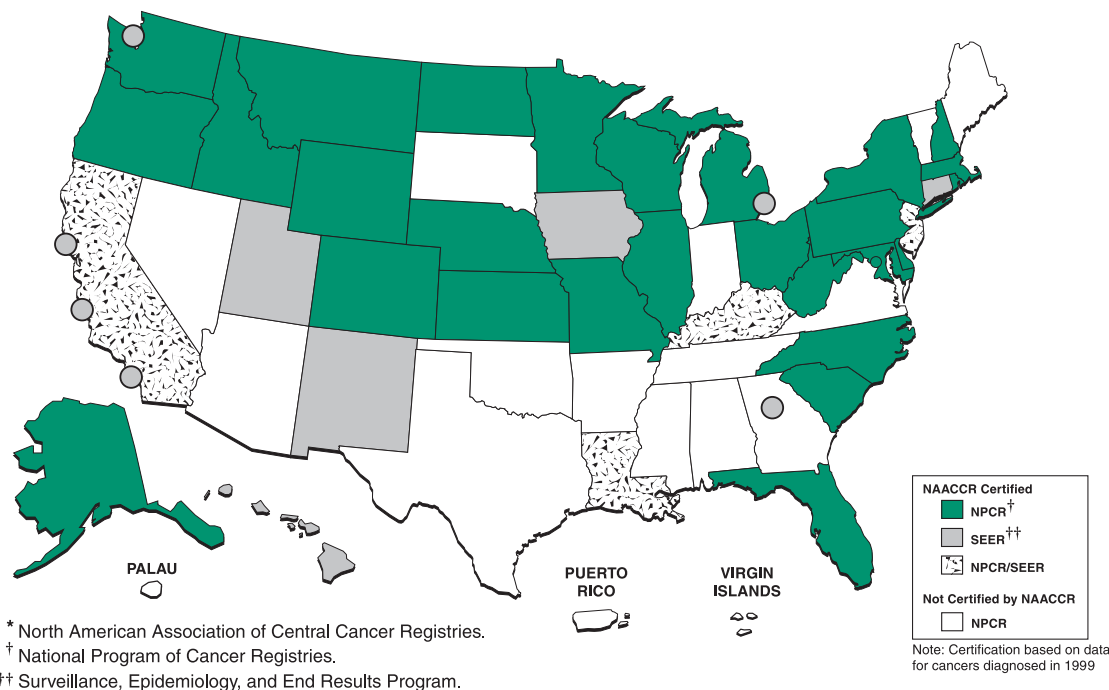
CDC has established national standards to ensure the completeness, timeliness, and quality of cancer registry

data. In addition, CDC recommends that central cancer registries incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR). In 1997, NAACCR instituted a program that annually reviews member registries' abilities to produce complete, accurate, and timely data. Registries that meet the highest standards receive NAACCR certification. Since this program began 6 years ago, the number of CDC-supported statewide registries meeting these high standards has increased from 9 to 32.

Implementing the NPCR–Cancer Surveillance System

NPCR has a unique opportunity to strengthen cancer reporting in the United States. NPCR registries collect information on cancer cases occurring among 96% of the U.S. population. In 2001, CDC began to receive state cancer data from these registries on an annual basis for entry into the NPCR–Cancer Surveillance System. This repository for cancer data is enabling CDC to provide valuable feedback to help state registries improve the quality and usefulness of their data and link with other databases. In addition, the availability of regional and national data is expected to facilitate studies in areas such as rare cancers, cancer in children, and cancer among specific racial and ethnic minority populations.

NAACCR* – Certified U.S. Cancer Registries: 2002



Using Data to Prevent and Control Cancer

NPCR enables reporting of cancer data by age, sex, race/ethnicity, and geographic area—within a state, between states, and between regions. Special emphasis is placed on obtaining cancer information on residents who travel to other states for diagnosis or treatment. Timely, accurate, population-based data on cancer incidence, stage at diagnosis, first course of treatment, and deaths are being used to evaluate cancer prevention and control efforts and progress toward health objectives. The examples below illustrate some of the many ways in which states are using registry data.



Colorado Central Cancer Registry data are being used to conduct an epidemiologic evaluation of cancer and occupational exposures at the Rocky Flats Environmental Technology Site. A roster of more than 20,000 current and former Rocky Flats workers is being matched against registry data files to examine cancer risks from radiation doses and chemical exposures.



The *Missouri Cancer Registry/Office of Surveillance, Research, and Evaluation*, in collaboration with the state's Center for Health Information Management and Evaluation, has developed a unique cancer information resource for citizens, health professionals, researchers, and policy makers. *Missouri Information for Community Assessment* is an easy-to-use, interactive Internet site where users can access both cancer statistics and information about risk factors.



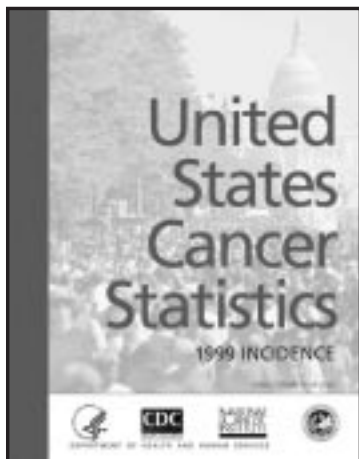
In a *New Jersey State Cancer Registry* study using geographic information systems, two areas in the northeastern part of the state were identified as having unusually high proportions of late-stage breast cancer. More than 90% of area women with a diagnosis of breast cancer lived within 2 miles of a mammography screening center. Demographic information showed that the populations of these communities tended to be black, Hispanic, or foreign born and to speak a language other than English at home. To increase screenings in these areas, New Jersey has produced culturally sensitive information about the availability of mammography in a variety of languages, including Arabic, Polish, and Spanish. The state also has provided training in cultural sensitivity and diversity to personnel at the screening centers.



From 1987 through 1999, the *California Cancer Registry* studied the incidence of cancer among members of the United Farmworkers of America, a largely Hispanic labor union. Results showed that the risk of leukemia and of stomach, cervical, and uterine cancers was elevated in California farmworkers. Union members also had a later stage of disease at diagnosis than other California Hispanics for most major cancer sites, but not for breast cancer. Additional research into the potential causes of this increased risk for certain cancers is planned, including a study of farmworkers' exposure to pesticides.

CDC Collaborations for Cancer Monitoring

In addition to providing financial and technical assistance to state cancer registries, CDC works with private-sector organizations, NCI, the Department of Veterans Affairs, the Indian Health Service, the Department of Defense, and other federal agencies to support cancer surveillance efforts. Following are several examples of these collaborative activities.



Annual Publication of Federal Cancer Statistics

In the fall of 2002, CDC's NPCR and NCI's SEER program, in collaboration with NAACCR, jointly produced the first set of official federal cancer incidence statistics from each state having high-quality registry data. The resulting report, *U.S. Cancer Statistics: 1999*

Incidence, exemplifies the progress achieved in creating a national system for cancer monitoring. This report provides state-specific and regional data for cancer cases diagnosed in 1999, the most recent year for which data were available. Cancer statistics from 37 states, 6 metropolitan areas, and the District of Columbia are included in the report; these areas contain about 78% of the U.S. population. Plans are to produce the report annually.

National Coordinating Council for Cancer Surveillance

CDC participates in the National Coordinating Council for Cancer Surveillance, a consortium that also includes ACS, NCI, NAACCR, the American College of Surgeons, and the National Cancer Registrars Association. The council provides a forum through which these organizations can collaborate on cancer monitoring and registry operations.

Report to the Nation on the Status of Cancer

Another collaborative project is the *Annual Report to the Nation on the Status of Cancer*. This document has been published annually since 1998. The 2002 edition, which included a special section on the implications of age and aging on the nation's cancer burden, was produced jointly by ACS, CDC, NAACCR, NCI, and the National Institute on Aging.

Special Research Projects

- **CONCORD Study: An International Collaboration**
The CONCORD study will measure and explore differences in cancer survival among cancer patients in Europe, Canada, and the United States. The study focuses on breast, prostate, and colorectal cancers.
- **Data Linkage with Indian Health Service Records**
The Indian Health Service (IHS) and the NPCR are linking data in 25 central cancer registries and the IHS clinical encounter database. This study is designed to improve the completeness of case reporting and to decrease the misclassification of American Indian/Alaska Native race.
- **Patterns of Care Study**
The NPCR Breast, Colon, and Prostate Cancer Data Quality and Patterns of Care study is designed to 1) use population-based cancer registry data to describe the patterns of care for cancer patients and 2) compare the quality of treatment and stage data in 10 central registries with reabstracted data from medical records.

For additional information on these and other research projects, please visit the following Web site:
<http://www.cdc.gov/cancer/ataglan.htm>.

Visit the PLANET—a collaboratively developed Web-based resource providing links to cancer-related data and evidence-based tools. The Cancer Control PLANET is designed to help communities better understand and address their cancer burden.
(<http://ccplanet.cancer.gov>)



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